

Summary of ECD Global Alliance chat held on Saturday 18th April 2009

7 Present

- One member reported that they are due to start a course of chemotherapy soon. They have been prescribed IV cladribine for four sessions, each session to last 5 days and then a gap of 3 weeks before the next cycle.
- One member told the group that they had been taking pegylated interferon for three months and had just had a CT scan which showed no changes. This member described the side effects that he experiences with this drug; it makes him a little dizzy and nauseous. On one occasion he felt very cold and was trembling, he took ibuprofen and felt better two hours later. One other member said they experience similar side effects whilst taking interferon and also use ibuprofen.
- A patient asked whether anyone else in the group has lung involvement; this patient has to use oxygen when walking any distance. Another member said that a CT PET had showed increased activity in the pleura of the lungs.
- A member enquired whether anyone else uses ibuprofen to help manage pain; two other patients said they take ibuprofen to help deal with pain.
- One member described their bone pain, (they are aware that ECD is in the bones) and that they would be requesting a bone scan to provide more information.